Carolina Lupus Study Newsletter

Number 6, December 2002

We had a very busy and productive year and we thank each of you for taking time to participate in the follow-up telephone interviews that were conducted in 2001. Our interviewing staff was personally touched by the health and life experiences that some of you are going through, both lupus patients and people without this disease. We were encouraged by how willing you were to help with the interview in spite of difficult life situations.

The First Follow-up Study of Carolina Lupus Study Participants

In 2001, a follow-up study was conducted with the Carolina Lupus Study participants. This study included a 45 minute telephone interview with patients and a 15 minute telephone interview with people who do not have lupus, focusing on current health status. We are beginning analyses of the follow-up interview data so you can expect to receive more news early next year.

Staff News

One of our North Carolina interviewers, Gwen McCoy is still working with us on various studies. The other North Carolina interviewer, Alesia Sanyika, worked with us on the follow-up study for a while but is currently working at the Raleigh Housing Authority. Our South Carolina interviewer, Sara Graham is still enjoying home.

Study Manager Lyle Lansdell is now working closer to home on a study at UNC Chapel Hill. Study Manager Glenn Heartwell led a new team to complete the Year 2001 follow-up study. Telephone interviewers were Cynthia, Carolyn, Robena and Rosa. Supervisor Lynda Tatum also completed some of the interviews. Many of you will remember Rosa as she was the nice lady interviewer who completed the very last interviews in January and also made reminder calls to those who agreed to send medical release forms.

Rob Campbell, a student in the Department of Epidemiology and Biostatistics at Case Western Reserve University in Cleveland, Ohio, will be working with Dr. Cooper this year. He will be analyzing the information regarding disease severity and quality of life that was collected in the first interview and in the follow-up study. Rob is from Charleston, South Carolina, and we are very pleased he has joined us.

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What Have We Learned So Far From The Carolina Lupus Study?

In previous newsletters, we summarized what we learned regarding the symptoms and clinical features of lupus, the relation between specific infections and other medical conditions and the risk of developing lupus, and the role of hormones in lupus. One of the biggest surprises was that we did not see the expected association between higher estrogen exposures (for example, from earlier age when menstrual periods began or later age at menopause) and increased risk of lupus. The effect of estrogen among women may be very different from the effect seen in the animal models of lupus. What follows is a summary of some other analyses we have completed. Just as a reminder, when we talk about "an association" or a "risk factor", it means something that was more common among people with lupus compared to people who do not have lupus.

Smoking

In contrast to some previous studies, we saw little evidence that smoking was associated with the risk of developing lupus: the percent of lupus patients who smoked was similar to the percent of people who do not have lupus who smoked. Of course, that does not mean that smoking is good for you, because many harmful effects of smoking are known (such as an increased risk of lung cancer and heart disease).

Use of Hair Dyes, Permanents, and Straighteners

About 10 years ago a study was published that indicated that use of hair dyes, permanents, and straighteners was strongly associated with risk of developing lupus. Since then, several other studies have been conducted, and none saw the type of results that were seen in that first study. We did not see any association between use of permanents or straighteners and risk of lupus, and we saw only a weak association with use of hair dyes. Taken together, the evidence now seems to be that use of hair dyes does not have a strong effect on risk of developing lupus.

Occupational Exposure to Crystalline Silica

Silica (also known as quartz) is a common mineral found in rock, sand, and soil. Breathing the smallest particles of silica dust can cause inflammation and scarring in the lung, and can cause the lung disease in workers known as silicosis. In the Carolina Lupus Study, we looked at what people told us on their job histories to see if lupus patients were more likely than people without lupus to have a history of silica dust exposure. We also called some people to ask them more about their work so that we would have a better idea of whether they might have been exposed to silica dust. More of the lupus patients had worked at a job that may have had a high silica dust exposure (the "dusty trades" such as construction work, pottery manufacturing, sandblasting and other abrasive blasting) and some very dusty farming tasks, such as mechanical tobacco planting and peanut harvesting. We saw similar results in women and men, even though women were less likely to work in the "dusty trades" compared to men.

An important contribution of the Carolina Lupus Study is that our results highlight the need to focus on occupational and environmental factors in addition to genetics in order to fully understand what causes this disease. If you need another copy of previous newsletters or would like more information, please call us at the toll-free number (on the front of this page) or check the National Institute of Environmental Health Sciences web site located at http://dir.niehs.nih.gov/direb/clu/home_clu.htm.

Thank you again for all of your help!